

ABOUT THE HOMELESSNESS RESOURCE CENTER

he Homelessness **Resource Center** fosters the development of an interactive learning community of providers, consumers, policymakers, researchers, and government agencies at federal, state, and community levels—with the goal of bringing together state-of-the art knowledge and promising practices to prevent and end homelessness among people with mental health and substance use disorders, and trauma histories. Our work includes training and technical assistance; publications; on-line

learning opportunities; and networking.

The Homelessness Resource Center is funded through a generous Contract (No. HHSS280200600029C) from the Homeless Programs Branch of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (SAMHSA), U.S Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the report authors and do not necessarily reflect those of SAMHSA or HHS.





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INTRODUCTION

People who experience homelessness also suffer from more cognitive problems than the general population. These may include problems with attention, memory, language and executive functions such as the ability to plan, organize, reason, prioritize, and solve problems. Sometimes described as "cognitive impairments" or "cognitive dysfunction," these problems are caused by disruption of neuropsychological processes due to traumatic brain injury, long-term substance use, schizophrenia, fetal alcohol spectrum disorders, or other issues than impact brain function. One meta-analytic review (Spence et al., 2004) identified 18 studies in which cognitive test data had been reported among a cohort of adults who were homeless. Where IQ was reported, it was generally found to be within normal limits. Yet when neuropsychological functions were assessed, cognitive impairment was frequently found. When the more sensitive tests that typically comprise a neuropsychological evaluation were used (Gonzalez et al., 2001; Solliday-McRoy et al., 2004, Seidman et al., 1997), the prevalence of cognitive problems approached 80%. Cognitive deficits in the adults experiencing homelessness were significantly greater than the proportion (2-3%) expected in an adult population. Memory and attention were most likely to be in the impaired range.

Cognitive impairments have been associated with problems in daily functioning as well as poorer social and vocational outcomes (Bates et al, 2004; Green, 1996). These difficulties can affect one's ability to interact with service providers and benefit from traditional psychosocial interventions, and educational and vocational programming (Backer and Howard, 2007; Solliday-McRoy, Campbell,

Meclchert, Young and Cisler, 2004). Deficits in perception, thought, memory and speech frequently trigger psychosocial problems, withdrawal, and isolation that can precipitate and prolong homelessness. It is not unusual for people with cognitive problems who are homeless to be "banned" from homeless service settings for disagreeable behavior or failure to comply with prescribed treatment or rules (HCH Clinicians' Network, 2003). Many of these individuals fall through the cracks of a fragmented service delivery system in which no one agency nor individual takes responsibility for them.

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Currently, there is very little treatment available for people who are homeless and have cognitive problems, particularly those who have little money and no health insurance. Furthermore, homeless service providers need to develop additional skills to work with people who suffer from cognitive problems. Recognizing this need, the Homelessness Resource Center convened an Expert Panel on Cognitive Impairment and Homelessness on June 17, 2008 in Rockville Maryland. The goals of the Expert Panel were to:



- Develop an understanding of the relationship among cognitive impairments, homelessness, and difficulty functioning
- Develop tips for service providers to guide their work with people who experience homelessness and cognitive impairment;
- Provide direction to the Homelessness Resource Center in future efforts related to cognitive impairment

Given the lack of treatment available to this population, the Expert Panel was asked to identify strategies and best practices for working with people with cognitive impairments that could be used in homeless services. The panel was comprised of experts with extensive knowledge of cognitive dysfunction and homelessness, homeless service systems, quantitative and qualitative research, and consumer involvement. Panelists included researchers, providers, program directors, policymakers, and consumers. A complete list of invited panel members is in Appendix 3. In preparation for the panel, members were sent the following materials to read:

- Putting Mental Retardation and Mental Illness on Health Care Professionals' Radar Screen by Rebecca Voelker, Journal of the American Medical Association.
- Improved Care for Neglected Population
 Must Be "Rule Rather Than Exception" by
 Rebecca Voelker, Journal of the American
 Medical Association.
- Cognitive Impairments and the Prevention of Homelessness: Research and Practice Review by Thomas Earl Backer and Elizabeth Howard, Journal of Primary Prevention Special Issue on Homelessness and Mental Illness.
- Cognitive Functioning in People who are Homeless by Alice Medalia and Evan Schwalbe, Columbia University.

The purpose of this report is to summarize the panel discussion by highlighting key issues, identified strategies and best practices, tips for providers, and next steps. The report is not intended to report verbatim what occurred at the expert panel, but instead to capture key messages, salient themes, and overarching concepts discussed by the panel.

SUMMARY OF EXPERT PANEL PROCEEDINGS

Defining the Problem: Cognitive Impairment and Homelessness

The Expert Panel began by addressing the core issues of homelessness and cognitive impairment. The group noted that individuals who are homeless have a vast range of needs including medical, psychological, social/ economic, and legal. For those who are cognitively impaired, the panelists identified additional obstacles in accessing services and entitlements and following through on treatment plans. These individuals "fail" programs because they have difficulty understanding and remembering to follow the rules and frequently cannot accomplish the tasks required of them. Often, people who are cognitively impaired and homeless will not reveal their disability for fear of being stigmatized or victimized. Providers are often unaware of the cognitive dysfunction as the individual will develop a cloak of competence that masks their disability. In vying for limited resources, they often lose out in the game of 'musical chairs" for housing and services. Not surprisingly, cognitive impairment is especially common among individuals who are chronically homeless.

Panelists identified cognitive impairment as a risk factor for homelessness. For individuals with traumatic brain injury, certain psychiatric illnesses and substance use disorders, early diagnosis and treatment could prevent homelessness. Additionally, children with cognitive dysfunction are oftentimes

misdiagnosed and/or go untreated and end up homeless as adults. Several panelists reported that the prevalence of Fetal Alcohol Spectrum Disorders (FASD) and its associated cognitive dysfunction among the prison population may be as high as 40%. Finally, veterans are particularly vulnerable to cognitive dysfunction because of traumatic brain injury and psychiatric disorders and are at high-risk of becoming homeless.

The panel suggested the population with cognitive impairments is "invisible" and often overlooked by homeless service providers. Sometimes the person who is subtlety cognitively impaired is not viewed as having a problem that needs attention but rather as a problem person. The panelists noted that providers have a tendency to describe a cognitive problem as a lack of motivation, and that providers may assume that cognition is not changeable, when in reality cognition may be highly malleable.

Several panelists identified the general lack of disability expertise among homeless service providers. Yet for clinicians, the origin of a person's cognitive issues is important for determining an appropriate treatment plan. Other panelists argued that cause or diagnosis of a person's cognitive impairment is not important because the focus should be on functional capacity. Some suggested that the professional boundary employed by most clinicians may create an unnecessary distance in their relationship with people with cognitive impairments. Instead, providers need to be flexible when working with this population to

establish authentic and trusting relationships. Finally, educating people who are homeless and have cognitive problems about their disability is important to remove the stigma of blame often instilled in these individuals.

The complexity and rigidity of most systems of care is a major barrier for individuals who have problems with thinking, memory, and judgment. Panelists identified disparities in accessing entitlements and benefits in rule-based organizations such as the Social Security Administration where forms must be completed in a particular manner and applications submitted within a certain timeframe. Systems of care tend to be overly complicated, and services are usually designated for specific groups with a common diagnosis. For example, a person who is homeless with cognitive impairments due to Fetal Alcohol Spectrum Disorders may be able to access Social Security Disability Income (SSDI) but be ineligible for housing assistance. Conversely, the client identified as 'slow' has difficulty navigating the homeless assistance network but is often not developmentally disabled enough to obtain services in the developmental disability system. In addition, they may not meet the age eligibility requirements. Funding for treatment of cognitive dysfunction is also restricted. Currently, Medicaid only reimburses for cognitive rehabilitation for people with a diagnosis of traumatic brain injury.

Panelists concluded this segment of the discussion by stating that people who are homeless with cognitive impairments do not have a "home" in the system of care. Cognitive impairment is an "orphan issue"

without a distinct system or group providing care, investigating and researching treatment modalities, or advocating on the behalf of this distinct population.

During the course of this discussion, it became apparent that terms and definitions related to cognitive impairment needed clarification. Before moving into the second half of the agenda, a discussion was initiated among the panelists to identify the provider group, define the term cognitive impairment, and clarify the distinct groups included among "people with cognitive impairments."

The panelists quickly agreed that the term "provider" in this context referred to people providing services to individuals who are homeless. Another panelist suggested the phrase "people who have problems with thinking, memory, reasoning and judgment with substantial limitations" in place of cognitive impairment. Many panelists agreed with this definition. Panelists recommended focusing on building skills and improving function rather than concentrating on the disability of cognitive impairment. For instance, one panelist suggested including cognitive rehabilitation within supportive employment programs.

Several panelists stated that people with cognitive impairments are a separate population from people who are mentally retarded or developmentally disabled.

One panelist asserted that people who are developmentally disabled are provided services within a distinct system of care with designated funding streams and they should not be considered part of the cognitively

impaired population. Another panelist disagreed and stated that people with mental retardation are one group of many with cognitive impairments. Other members asserted that people who are developmentally disabled can have cognitive impairments but not all people with cognitive impairments are developmentally disabled.

Others suggested that addressing cognitive impairment in the homeless population could be viewed like universal precautions or trauma-informed care. Essentially, strategies to enhance cognitive functioning would be employed by all providers when working with people who are homeless. Others stressed that the focus should be on building skills regardless of the origin of the cognitive impairment.

The panel did not reach consensus on all aspects of this discussion of terms and definitions.

Through the course of the expert panel, participants raised critical issues and themes that will provide guidance to the Homelessness Resource Center. While these themes were in most cases echoed by multiple panelists, the list is not necessarily based on consensus across the entire group. Rather, Homelessness Resource Center staff identified points that captured the essence of the dialogue. Emerging themes included:

- 1. People who are homeless are more likely to experience cognitive impairment than those who have stable housing.
- Causes may include traumatic brain injury, schizophrenia and other psychiatric disorders, Fetal Alcohol Spectrum Disorders, developmental disabilities and long-term substance use.
- 3. People who are homeless and who have cognitive impairments are often stigmatized and labeled with terms such as "non-compliant," "resistant," or "unmotivated."
- 4. Many strategies exist to serve people who have problems with memory, attention, and problem-solving ability but these strategies exist within different systems of care and need to be brought together.
- 5. Homeless service providers need training to equip them with these skills and strategies.
- 6. Programs that stress cognition like motivational interviewing may need to be modified for people with cognitive impairments.

[&]quot;Universal precautions," as defined by Centers for Disease Control and Prevention (CDC), are a set of precautions designed to prevent transmission of bloodborne pathogens when providing first aid or health care. Under universal precautions, blood and certain body fluids of all patients are considered potentially infectious.

Trauma-informed care are services that involve understanding, anticipating, and responding to the issues, expectations, and special needs that a person who has been victimized may have in a particular setting or service. At minimum, trauma-informed services should endeavor to do no harm – to avoid re-traumatizing survivors or blaming them for their efforts to manage their traumatic reactions."

Strategies for Preventing Homelessness, Improving Systems and Training Staff

The panel then identified specific strategies for people who are homeless with cognitive impairment. Based on the earlier discussion of major issues, the panel broke into three small groups: Homelessness Prevention, Systems Improvement, and Staff Training. Each group listed as many strategies as they could identify, then reported back to the entire panel. Highlights are presented below.

HOMELESSNESS PREVENTION STRATEGIES

Panelists in this group discussed prevention strategies for homelessness and cognitive impairment. The strategies ranged from a focus on preventing homelessness to assisting people who are homeless with cognitive dysfunction in obtaining and maintaining housing.

- Create policies that ensure cognitive impairment is not a basis for excluding people from housing.
- Provide a range of housing types with a minimum standard of cognitive supports; for example, a Learning Center in every housing facility that contained cognitive supports.
- Convene a government-sponsored task force to generate consensus on sensitive and relevant cognitive assessment tools.
- Create and distribute quick and sensitive screening tools for identifying cognitive functioning.

- Assess cognitive skills as part of discharge planning from corrections systems,
 Veterans Affairs, foster care, and other systems.
- Consider assessing cognitive skills for functioning in housing after an individual is housed to ensure assessment is not a barrier for excluding people from housing.
- Teach functional skills (e.g. filling out forms, writing a check) in elementary and secondary education.
- Publish educational handbook for families with members who are cognitively impaired.
- Educate the general public about homelessness to shift cultural values to "housing is a right and not a privilege."
- Develop and disseminate fact sheets and tools to increase awareness about cognitive impairment and homelessness.
- Fund and implement initiatives that promote accessibility to services, such as SSI/SSDI Outreach, Access and Recovery (SOAR) Initiative.

STRATEGIES FOR IMPROVING SYSTEMS

Strategies generated by panelists in this group were directed at several different systems including the federal government, systems of care, and organizations.

- Identify best practices for implementing changes at the systems level. For example, Canada recognizes intellectual disabilities and diagnoses in their health care system.
- Advocate for a move from rule-based organizational systems to value-based systems of care.

- Provide multiple points of entry into systems of care.
- Identify outcome measures based on intensity of services rather than volume of services.
- Request SAMHSA to conduct a study on the best practices for treating cognitive impairment in persons experiencing homelessness.
- Ask federal officials to visit programs working with people who are cognitively impaired and homeless.
- Publicize those programs that produce cost savings while providing quality care.
- Shift the burden of determining eligibility for services from the individual to the organization.
- Identify and develop cultural competencies for working with people who are homeless with cognitive impairments.
- Develop strategies for overcoming privacy issues so resources can be shared.

TRAINING STRATEGIES

Panelists suggested targeting several groups of direct service providers for training, including health care providers, behavioral health clinicians, housing and shelter staff, and front desk staff in organizations that serve people who are homeless. The panel recommended ongoing training in person and online. Several key components of training were identified:

 Overview of cognitive dysfunction, including the various neuropsychological causes and their relationship to a person's behavior.



- Skills-building on how to engage and negotiate with people who are homeless with cognitive impairments by responding rather than reacting to specific behaviors.
- Strengths-based approach to care that identifies the individual's positive resources and abilities.
- Service package that increases functional skills with a practical list of techniques.
- Skill and support interventions based on the goals the individual has identified.
- Focus on mentoring rather than traditional case management.
- Environmental adaptations to accommodate and support people who are homeless with cognitive impairments.
- Characteristics of a value-based organization and strategies for changing organizational culture.

Best Practices and Tips for the Field

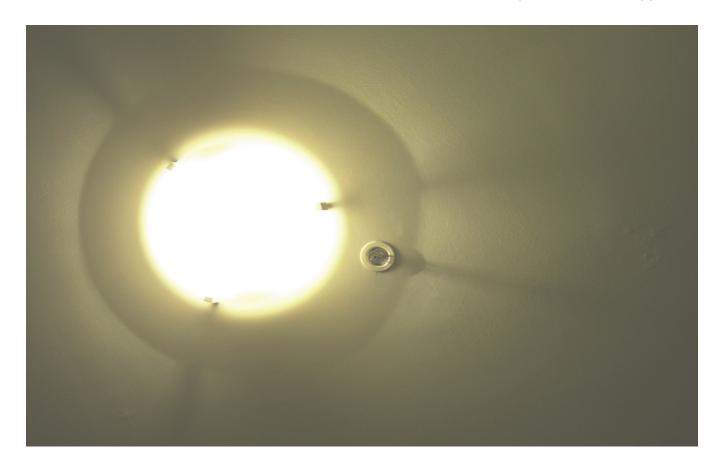
Given the lack of support for treatment available to people who are homeless with cognitive impairments, the panel was asked to identify best practices that could be implemented in homeless services. The process involved small groups identifying as many best practices as possible and reporting back to the entire panel. Best practices that are becoming widely used in the homelessness field include:

- Housing First
- Supported Employment
- Harm Reduction

- Assertive Community Treatment (ACT)
- Outreach to people who are homeless
- Collaboration between the Department of Housing and Urban Development and Veterans Affairs on supportive housing for veterans who are homeless
- Case managers onsite at housing projects
- Case managers with manageable case loads

Other best practices identified by the panelists are not widely used in homeless services but may be emerging in other fields or with other populations. These include:

 Learning Centers in supportive housing to improve cognitive skills through an individualized, person-centered approac



- Cognitive impairment training for case managers and residential program staff.
- Strengths-first approach to care
- Physical, intellectual, and emotional skills recovery
- Alumnae of cognitive rehabilitation program mentoring new members
- Peer support at all levels of the program
- Functional needs assessment and individualized treatment with a focus on what the person wants to accomplish
- Environmental supports that enhance cognition (e.g., key hook by the front door to help someone remember where they put their keys)
- Creating systems of care that build intrinsic motivation to function at highest level in the community
- Life skills coaching

Panelists also identified other promising practices utilized in specific agencies or communities:

- Brain Injury Association of Minnesota <u>www.braininjurymn.org</u> collaborates closely with homeless services
- Montgomery County, Maryland provides case management for people who are homeless with disabilities. The county provides a grant for mental health services and collaborates with the county's homeless coalition
- Services at the Center for Psychiatric Rehabilitation at Boston University are delivered using education as a framework

as it immediately gives people the valued role of a student, rather than a patient, consumer, client, or a diagnosis. The Recovery Education Program at the Center is an adult education program that offers students the opportunity to choose a range of wellness courses that support their treatment, rehabilitation, and recovery efforts

The panel distilled the following overarching principles that were present among the best practices:

- Work on goals identified by the client as important to them
- Promote mentorship among peers
- Foster individual relationships by allowing buddies to accompany individuals during provider visits
- Identify ombudsmen who advocate for individual clients
- Provide wrap around services that are easy to access
- Provide services where people are shelters, housing, on the street
- Implement flexible rules that foster sobriety
- Plan to spend time assisting clients in deciphering multiple systems and moving through the "kaleidoscope of care"

The panel was also asked to generate practical "Tips for the Field" which could be disseminated quickly and used immediately by homeless service providers. A list of these tips can be found in Appendix 1.

WHERE DO WE GO FROM HERE?

Based upon the discussions of the expert panel and drawing on the work of the breakout groups throughout the day, panelists suggested several next steps to guide the work of the Homelessness Resource Center related to cognitive impairment and homelessness:

- Advocate for regulatory changes to improve the support and services. See the Consortium for Citizens with Disabilities website http://www.c-c-d.org and the Center for Lobbying in the Public Interest http://www.clpi.org
- Advocate for providers and others to join mailing lists for legislators, participate in telephone town meetings, and testify at hearings
- Assist providers in identifying funding streams to support cognitive treatment.
 For example, bill cognitive services under psychiatric rehabilitation or supportive employment
- Analyze how much money is spent in each state on cognitive impairment and explore cost-benefits
- Promote basic research on cognitive impairment and homelessness that explores which strategies work best with specific homeless populations
- Develop strategies to translate best practices from other fields into homeless services, e.g. Center for Psychiatric Services at Boston University

- organize trainings about cognitive impairment and homelessness and present at national conferences and at regional trainings. Engage mainstream providers in trainings and promote cognitive impairment trainings by other provider groups through the Homelessness Resource Center website (homeless.samhsa.gov)
- Collaborate with SAMHSA Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence (www.fascenter.samhsa.gov)
- Publicize "Tips from the Field" (Appendix 1) on the Homelessness Resource Center website
- Create videos of stories from individuals who are homeless with cognitive impairments and disseminate them using social networking technologies such as YouTube and the Homelessness Resource Center website
- Conduct a public awareness campaign about chronic homelessness and cognitive impairment
- Coordinate homelessness and cognitive impairment efforts across federal agencies
- Get involved with State Medicaid
 Directors and State Intellectual Disability
 and Developmental Disability Directors to
 elp develop their state plans.

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APPENDIX 1: TIPS FOR THE FIELD

Homeless Service Providers should keep the following tips in mind:

General tips

- Listen to the person who is in front of you. Be present. Be authentic.
- Always use person first language.
- Let people finish their sentence.
- Agree with what you can agree with when working with a client.
- Listen to the person's personal story.
- When the client is seated, sit down when interacting with them.
- Come out behind the desk and sit next to the person.
- Recognize and advocate against stigmatizing language.

Specific Tips

- Write down what is to be remembered.
 Put it where a daily activity occurs such as in the bathroom.
- Ask clients to repeat back what they heard.
- Repeat directions and plans frequently.
- Break down instructions into tiny steps.
- Respect person's inability to focus for a long time by keeping appointments short.
- Remind clients by using instant message on their phones.

Assessment tips

- When explaining procedures or rules, ask clients "What does that rule mean to you and show me how you would do that rule?
- To determine level of education obtained by the client, ask "How long were you in school?" to discover level of education, and to discern whether they attended special education.
- In determining a plan, ask "What do you want to do and how can I help you achieve that?"
- Ask people to read to you to find out their reading abilities.

Tips for Organizations

- Keep rules few, simple and flexible.
- Assume that not following a rule is not deliberate.
- Write down names of medications and contact information for providers.
- Have one phone line to call in for prescriptions for all of the providers in the organization.
- Ask for cell phone numbers and email addresses from clients.
- Require welcoming skills as a competency for all front desk staff.
- Decrease stimuli in environment to reduce attention overload.
- Schedule an appointment for the client before the office gets too busy.

APPENDIX 2: EXPERT PANEL AGENDA

February 11, 2008

Great Falls Room SAMHSA

1 Choke Cherry Road Rockville, Maryland

Agenda

8:30	Welcome	Kathryn Power	
8:45	Introductions and Review of the Day		
9:00	Background	Ellen Bassuk and Jeff Olivet	
9:30	Discussion : Developing a working model for identifying effective practices in the homelessness field		
10:30	Break		
10:45	 Breakout Groups Discuss and Report Out to Full Panel How do we identify effective practices in the field? What are some of these practices? 		
11:45	Lunch		
12:30	Summary of the Morning's Work		
12:40	 Breakout Groups Discuss and Report Out to Full Panel 1. Integrating and strengthening existing evidence in homeless services 2. Translating research into practical applications 		
2:15	Break		
2:30	Discussion : Next Steps		
3:30	Adjourn		

APPENDIX 3: LIST OF PARTICIPANTS

Panel Members

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FREQUENT FLYERS
NONCOMPLIANT
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RESISTANT
MANIPULATIVE
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NOT TRYING HARD ENOUGH

NEEDY MALINGERER OBNOXIOUS RUDE LOUD INTRUSIVE DEPENDENT CRAZY DISRUPTIVE MENACING VIOLENT THREATENING COGNITIVELY IMPAIRED AGITATED UNPREDICTABLE

Stigmatizing labels identified by the Expert Panel used to describe people who are homeless with cognitive impairments.